



**ARIZONA SUBSTANCE ABUSE TASK FORCE
Neonatal Abstinence Syndrome Work Group**

June 30, 2016

1:00 p.m.

Governor's Executive Tower

Suite – 230

1700 West Washington Street

Phoenix, Arizona 85007

A general meeting of the Neonatal Abstinence Syndrome Work Group was convened on June 30, 2016 at 1700 Washington Street, Suite 230 Phoenix Arizona, 85007, notice having been duly given.

Members Present (7)

Debbie Moak, Governor's Office of Youth, Faith and Family

Beckett, Cindy, Flagstaff Medical Center

Kate Brophy-McGee, Legislator

Jennifer Carussetta, Health System Alliance of Arizona

Elaine Ellis, Phoenix Children's Hospital

Deb Gullett, Arizona Association of Health Plans

Rick Sloan, Compassionate Care Centers

Staff/Guests Present (3)

Sharon Flanagan-Hyde, Flanagan-Hyde Associates

Rene Bartos, Mercy Maricopa, Presenter

Kathy Davis, Member of the Public

Members Absent (3)

Glenn Waterkotte, Retired Neonatal Abstinence Syndrome Doctor

Michael White, Community Medical Services

Thelma Ross, Community Member

A. Call to Order

Co-Chair **Debbie Moak** called the meeting to order at approximately 1:00 p.m.

B. Welcome and Introductions

Sharon Flanagan-Hyde asked the work group members to introduce themselves. She reminded the group of their norms which included:

- Members are to speak candidly.
- One person should speak at a time.
- Be respectful.
- Self-monitor to ensure there are no tangents.
- Work toward consensus.

C. Approval of the Meeting Minutes

The meeting minutes for the May 12, 2016 meeting were approved without modification/change.

D. Volunteer to Report at the Task Force Meeting

Sharon asked for a volunteer to report on the Neonatal Abstinence Syndrome (NAS) Work Group's updates at the Arizona Substance Abuse Task Force meeting that is scheduled to occur on August 24, 2016. Kate Brophy-McGee agreed to report to the Task Force.

E. Presentation: What Stood Out?

- The Lily's Place presentation was fantastic and it was fantastic to hear about the progress being made with the babies at that facility.
- Makes sense to facilitate the creation of a facility like Lily's Place possibly connected to a hospital.
- Alternatives to the NICU make good sense.
- The book (*How to Create a Neonatal Withdrawal Center*) was a great read, very thorough, and outlines how to create an environment like Lily's Place.
- An environment like Lily's Place is a solution which will save money.
- The concept should include the mothers all the time and there is a grave concern about separation of mothers and babies overnight.
- There is a concern about not dealing with the mother's substance abuse.
- These babies are medically fragile babies and the requirements to return them home need to be looked into with DCS.
- The requirements of foster parents are much stricter than the requirements for biological parents.
- There has to be some requirements for biological parents to receive the child, the parents must pass the same kind of test as foster parents. Just because they are the parents doesn't entitle them to take the babies.
- There are situations where rooming in isn't possible such as when the mother leaves the baby at the hospital and goes.
- Where we can reunite mom and baby safely, standards need to be in place.
- Different standards apply to birth parents then to foster parents.
- When a mother does go in for prenatal care and says I need help, it would be good to create some sort of directory or resources available for obstetricians to get women into treatment.
- Support connections between different care groups.
- Lily's Place is a great concept but we need to make sure when looking at best practices that they are comprehensive and look at the family.
- NAS is a complex issue and there should be graduated care including both the hospital and places like Lily's place.

F. NAS Initiative Presentation

Presentation was provided by **Dr. Rene Bartos**. The following was presented at the meeting:

- There are links in the presentation which people can access.

- Hopes to add onto discussion from prior presentations.
- Mercy care has a little fewer than 400,000 members and many are mothers and babies.
- Mercy Care performs services in all lines of business.
- SEN and NAS are complex and can be the result of combinations of different types of drug exposure.
- NAS has become more common and more complex in terms of substances involved.
- Dr. Bartos originally got involved with NAS issues on the SEN task force and tried to work on the issue from the health plan perspective.
- Mercy Care set out to create a program to address NAS and have now implemented that program along with Mercy Maricopa.
- They are trying to get all the health plans on board, AHCCCS and commercial, to work on best practices that all health plans should be implementing.
- They got all the AHCCCS health plans on board and in the SEN work group.
- NAS needs to be thought of as a continuum and past the neonatal period.
- Recent study shows children with NAS are more likely to be hospitalized later in childhood even after adjusting for prematurity.
- NAS has gone up 235% since 2008.
- Mercy Care utilized the goals of the SEN task force to see what they wanted to do and impact.
- First looked at data from Mercy Care Plan, looked like there was an underreporting problem from 2012-2013 even when adding in all substance related codes.
- Are providers asking pregnant women about prescription opioid use?
- Providers are listing substance use as illicit substances and therefore not always reporting prescription opioids.
- Worked alongside Mercy Maricopa who have implemented similar program.
- How can we identify pregnant women and get them into case management?
- Mercy Care plan have found ways to increase identification of women.
- Developed model for case management if both mother and baby are members.
- Developed system of referrals for support and special services.
- Enhanced data tracking.
- Parent/guardian brochure provides information about NAS to parents and foster parents who take in a baby with NAS.
- Mercy Care provides the Pregnancy Connection newsletter.
- Provider outreach document which provides NAS best practices.
- Goes through prevention strategies as well as best practices for managing both mother and baby.
- Some of the children are removed from the home and become CMDP members and are no longer Mercy Care members. Mercy Care is trying to coordinate with CMDP in those situations.
- Treatment issues include many different providers who aren't always connected such as pain management and obstetricians.
- Mercy Care is trying to promote provider best practices.
- Providers should utilize opiate prescribing guidelines.

- Advise women of child bearing age about NAS.
- Best practices during childbearing years include determining if a woman is pregnant before prescribing opiates.
- Identify substance use through testing urine.
- Advise women about opioid use during pregnancy.
- MAT during pregnancy resulted in babies possibly being born with NAS but the babies are less likely to be premature and better outcomes than those who detoxed.
- Best practice is to refer pregnant member to case manager.
- Give out a phone number so members know where to go to get information.
- The American Congress of Obstetricians and Gynecologists (ACOG) states that best practice is MAT for someone dependent on opioids.
- Key thing is having all facilities using an evidence-based screening and treatment protocol for newborns, consistent staff training, and consistency in how staff scores NAS babies.
- Non-pharmacological treatment first is a best practice. This includes low lights, quiet environment, and not waking babies up when you don't need to.
- Not every baby with NAS needs weaning protocol with medications.
- Utilize correct coding so the plan knows what is going on and the incidence of NAS.
- Breastfeeding is only contraindicated with street drugs.
- Providers sometimes not comfortable with breastfeeding because they don't know if opioid use is a prescription or street drug.
- Nurses notice everyone around the state is using different protocols for how to treat NAS.
- Seems like people are trying things out and it is unclear what is working and not working.
- Doctors are less willing to let a baby go to a lower-level facility because they are afraid the baby will get worse and need to be readmitted.
- Studies show benefits of rooming in and couplet care.
- Quality improvement collaborative study shows reduced length of stay and reduced cost associated with rooming in and couplet care.
- Average length of stay decreased, costs per infant dropped, cumulative morphine dose dropped, no adverse events, and readmission rates remained stable.
- Don't know long term-effects on the baby of the drugs used to wean from opioids.
- It is good practices that if you don't need medications, then to first do no harm.
- Rooming in helps with the bonding with the parents.
- Where should the baby be after delivery if not the NICU?
- Some have a facility in or next to the hospital.
- Casa de los Niños is a subacute facility in Phoenix willing to take NAS babies, however, some doctors don't feel comfortable letting babies go there because the location is far from the parents' home; concerned that there is only one location and distance from family may reduce bonding.
- If Lily's Place model is used there may need to be multiple locations to allow for proximity to homes.
- Mercy Care trained staff that NAS should always be treated as a high needs baby.
- Implementing case management which includes mother and baby.

- Providing outreach materials and community education.
- Challenges include under reporting, obstetricians who are not willing to manage opioids during pregnancy, provider coordination, immediate weaning, variation in protocols, inability to use the same case manager for mother and baby in some cases, and difficulty contacting members.
- Members complain they don't know what to do and pregnant members are concerned about stigma and DCS involvement.
- No decision about the baby's discharge plan until last minute in some cases.
- Health plans have a real ability to impact this issue in Arizona.
- Is there any Arizona data on the re-hospitalization rate and increased malnutrition rates?
- We don't have data, only because this topic has been limited in the past and was seen as a newborn problem.
- Can look for how to get it here, problem is you need to have the correct coding in the first place to get accurate numbers.
- There is a difference between a mom who wants to do the work towards being a good parent and those who are completely addicted and sometimes there is no putting the family back together.
- It is one thing if you just have a child maltreated because parents don't want to be parents.
- There was a lengthy discussion about all the factors in the study itself.
- There is a risk factor with mom who wants to do everything right and the druggie mom who just wants the baby and we have to be able to score the risk to that child going forward. The challenge of the system is figuring out which mom should keep custody and which shouldn't.
- Need to be careful because people recover; with great detox and treatment you can become whole again and where do you draw that line.
- When possible and you remove these substances and people recover how do you find that line and determine if they can keep the child.
- Stop prescribing opioids to women of childbearing age.
- National attention to this is getting somewhere and people are thinking about what they are doing when prescribing.
- Toxin effects and indirect effects are difficult to separate.
- The focus should be on promoting bonding and less pharmacological treatment
- What about drug testing pregnant moms, is it done or is it a recommendation?
- Wants obstetricians to question pregnant women, assuming they go in for prenatal visit at all, and get them to use a screening tool.
- Not sure if urine testing should be mandated as it may prevent women from coming in for a prenatal visit.
- Some obstetricians may do testing for substances but first you need to consider prescription opioids as part of the problem.
- Taking a step back and educating obstetricians to consider prescription opioids as a problem could go a long way.
- Heroin is going up even when prescription is going down and death is staying the same.

- People will turn to heroin when they can't get prescriptions.
- Family doctors aren't treating pain any more sending to pain management and view opioids as a liability.

Long Term Outcomes of Substance Abuse Presentation

Presentation was provided by work group member, **Cindy Beckett**. The following information was shared:

- Half of all women are drinking on regular basis.
- 18-25 year olds have huge amounts of alcohol consumption.
- Half of pregnancies in AZ unplanned.
- Fetal alcohol piece of this conversation is huge and greatly under reported.
- Increase in NAS across state in past few years.
- What happens after NAS?
- Reality is the babies have already been exposed to effects, some more impactful than others.
- After recovering, learning disabilities on a huge spectrum, social and behavioral issues sometimes leading to violence, substance use and abuse when they get older and mental health challenges.
- Why do these issues occur?
- There can be issues in the first few days or weeks of pregnancy.
- The timing of the ingestion of drugs or alcohol is critical.
- First 12 weeks are critical because systems are being developed and organs formed.
- Some mothers may not even know they are pregnant at this point.
- Time of ingestion, amount, and frequency of use impact the severity of effect on baby
- Physical and brain damage can occur.
- The cause of most defects remains unknown.
- Cause of disability remains unknown.
- Some can be linked to drug exposure but some are genetic or other causes.
- If drugs and alcohol are not ingested during pregnancy we can at least assure that they won't contribute to birth defects.
- Can be physical, developmental, cognitive, and behavioral damage.
- Baby will appear normal if the mother stopped drinking prior to the birth.
- The sole cause of FASD is drinking alcoholic beverages.
- No safe amount of alcohol to consume during pregnancy.
- FAS happens in small percentage of babies including the physical conditions, FASD is more common.
- FASD is a pattern of difficulties associated with alcohol.
- Can affect organ system if ingested in first few weeks.
- Alcohol exposure can cause structural damage; can cause cleft lip or palate.
- Alcohol can impact central nervous system, which usually happens if exposure is in the 16th week of pregnancy.
- Not just structural damage, once organs are formed then it impacts brain development.
- Low IQs, learning disabilities, less balance, sensory deficits, troubles with information processing, and decision making are all effects of FASD.

- No one would give a baby alcohol.
- FAS is a medical condition and only 15% qualify for DD services.
- Difficult to diagnose and sometimes isn't discovered until 3-5 years of age if they don't have facial features typical of FAS.
- Often times parents know something is wrong but do not know why.
- If diagnosis occurs before age 6, early intervention services can be provided.
- Only 1 dysmorphologist in the state of Arizona.
- Easier to identify if the mother drank all the way up to delivery because the baby will have symptoms and test positive for alcohol.
- Need documented maternal alcohol use in order to diagnose.
- Seeing paternal alcohol abuse linked to FASD.
- Don't respond to normal behavioral modification treatments.
- Early school dropout, joblessness, trouble with the law, unable to care for own children, and premature death are secondary impacts of FASD.
- One study said between 70-80% of inmates may have had alcohol exposure at some level.
- May be a secondary drug of choice with other drugs as well.
- Cocaine can result in premature birth, placental abruption, decreased birth weight, and other effects.
- Meth can result in preterm birth, placental abruption, increased SIDS, and learning disabilities among other effects.
- Marijuana can result in congenital heart defects, and other effects.
- Opioids can result in NAS, low birth weight, and long term behavioral problems among other effects.
- When babies are exposed to drugs and alcohol at minimum you will likely see learning disabilities.
- More exposure increases risk.
- If drinking in the first twelve weeks you may see physical defects.
- Social and behavioral issues are huge in the literature.
- Not out of the woods after they are sent home from withdrawals.
- Important for children and cost effective if we get early intervention and diagnosis.
- If you don't qualify for DD, doesn't mean you shouldn't get services.
- Won't find addiction in notes so none will qualify if that is how it is looked at for Asleep.
- Limited mental health services for those under adolescent age.

G. What Recommendations should be in the Task Force's Report in October?

- Review and update of the screening protocol for universal urine drug screening at the time they present for prenatal care and labor and delivery.
- Emerging research and best practices indicate the NICU not always best place.
- All providers in state are made aware of NAS.
- Support alternatives including Casa de los Niños.
- There needs to be a risk assessment on behalf of just the baby.
- Need to have foster option at the Lily's Place type setting.

- Support for a stand-alone facility including one in or near a hospital with option for mother to be there 24/7.
- Need a pathway or model for placing children.
- The follow up and engagement need to be longer, should not send a high needs baby home as quickly as we are now.
- Hospitals should have flexibility.
- There needs to be a continuum approach.
- Ability to keep mother and baby on same health plan if possible or more coordination of care.
- Mother and baby as a treatable unit might make sense.
- NAS should be sent over when plans transfer.
- When you get naloxone, urine should be tested for pregnancy.

I. What Additional Information Do You Need?

- None

J. Call to the Public

Kathy Davis answered the call to the public.

- Neonatal nurse in the valley.
- Ultimately mother and baby is the concern.
- Not always an option to keep mother and baby together.
- Most staff not trained to do the scoring.
- Nurses are just given a population and have to take care of them.
- Scoring always remains subjective.
- Standard for care is morphine, secondary medication if morphine is not effective.
- Hospitals are short staffed.
- Rooming in first if mother stays; only intervene if score is 3 scores above 8.
- Not all babies score above 8.
- DCS is notified when that occurs.
- Casa de los Niños is a whole different population; same population as hospital and not a quiet, nurturing environment.
- Current system cannot keep up with the demand.
- One nurse for four moms and four babies.
- Staffing just not there.
- There is not alcohol testing for babies or moms.
- Suspicious behavior could result in a drug test.
- Lily's Place provides for mothers and babies.
- Many mothers drop off over the 30 days it takes to get the baby well.

K. Adjourn

Debbie adjourned the meeting at approximately 2:55 p.m.

Dated July 5, 2016
Arizona Neonatal Abstinence Syndrome Work Group
Respectfully Submitted By:
Kyle Sawyer
Arizona Health Care Cost Containment System

DRAFT